

DOCUMENT RESUME

ED 116 384

EC 080 755

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TITLE What Are We Waiting For? The Problem Is Growing. A Report of a Conference on Early Intervention with High-Risk Infants and Young Children.
INSTITUTION Association for Childhood Education International, Washington, D.C.; President's Committee on Mental Retardation, Washington, D.C.
REPORT NO DHEW-OHD-75-21011
PUB DATE 75
NOTE 30p.; Conference on Early Intervention with High-Risk Infants and Young Children (Chapel Hill, North Carolina, May 5-8, 1974)
EDRS PRICE MF-\$0.76 HC-\$1.95 Plus Postage
DESCRIPTORS Conference Reports; *Demonstration Projects; *Early Childhood Education; Educational Needs; Exceptional Child Research; *Handicapped Children; Identification; Infancy; *Intervention; *Research Reviews (Publications)

ABSTRACT

Summarized are conference presentations on the following topics: relevant research (in areas such as mother/child interaction); eight demonstration projects (such as the Portage Project); case finding, screening, diagnosis, and tracking; the University of North Carolina's intervention programs; and the state of the art of early intervention. Listed are over 30 recommendations which were generated by conference committees in the following areas: education, pediatrics, nursing and rehabilitation, community development, parents, and research. A list of conference participants is provided. (LS)

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THE
PROBLEM
IS GROWING

What Are We Waiting For?

*A Report of a Conference on Early Intervention
With High-Risk Infants and Young Children*

*The University of North Carolina
Chapel Hill*

May 5-8, 1974

Sponsors:

*The President's Committee on Mental Retardation
Washington, D.C. 20201*



*Association for Childhood Education International
3615 Wisconsin Avenue, N.W.
Washington, D.C. 20016*



U.S. DEPARTMENT OF HEALTH,
EDUCATION & WELFARE
NATIONAL INSTITUTE OF
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The President's Committee on Mental Retardation
Washington, D.C. 20201

1975

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we
gratefully
acknowledge...

...the cooperation and support of the
conference by the following agencies of the U.S.
Department of Health, Education, and Welfare:

National Institute of Child Health and Human
Development

Bureau of Education for the Handicapped
Developmental Disabilities Division

National Institute of Mental Health
Office of Child Development

We also appreciate the assistance of Dr. James
Gallagher, Dr. Don Woods, Joe Sanders, and other
members of the faculty and concerned staff of the
University of North Carolina at Chapel Hill, whose
efforts in planning, public relations and logistics
made the conference a success and a pleasure.

Each successful conference is dependent on a special
group of leaders. Appreciation for their leadership
is extended to Alberta L. Meyer of the Association
for Childhood Education International; the
co-chairpersons, Dr. Will Beth Stephens, PCMR
Member, and Dr. Theodore Tjossem of NICHD;
and the PCMR staff coordinator for the conference,
A. D. Buchmueller.

FRED J. KRAUSE
PCMR Executive Director

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Library of Congress Catalogue No. 75-600085
DHEW PUBLICATION NO. (OHD) 75-21011

The Conference

Children are ready to learn from the time they are born. Parents are ready to teach them. Teaching tools are available. Professionals know how to use these tools to help parents help their children. But here the links of the chain often fail to connect.

What are we waiting for?

The time lag between a child's readiness to learn and the start of appropriate mental stimulation can often determine the extent of ability—or disability—for life. This concept was a major theme of the Conference on Early Intervention With High-Risk Infants and Young Children held at the University of North Carolina at Chapel Hill, May 5-8, 1974.

The conference was called by the President's Committee on Mental Retardation and the Association for Childhood Education International. The University of North Carolina's Child Development Institute was the host.

The first presentations were on basic research. Discussions then proceeded to applied research, followed by demonstration, and, finally, application of current knowledge.

Participants included educators, physicians, biological and behavioral researchers, nurses, social workers, federal officials, parents, professionals from Canada and South America, and others concerned with children at risk from either biological or environmental causes.

There was a recurring call for full partnership among parents, educators, physicians and community leaders to share their knowledge and experience to help all children—especially high-risk children—to develop as normally as possible.

"We do not have all the answers," said Dr. George Tarjan, in summarizing the conference, "but we do know enough to promise to the next generation of high-risk infants that there will be progress rather than regression."





REVIEW OF RELEVANT RESEARCH

The conference topics ranged from a microscopic view of very early development of neural connections in the infant brain to parental involvement in treatment programs.

As the discussions progressed, these disparate subjects came together in an interrelationship that pointed up the necessity for interaction of all disciplines in order to achieve the highest quality of life possible for each child who is retarded or is in danger of retardation from biomedical or other causes.

Dr. Morris Lipton gave participants a basic example of such interaction within each individual. There is now good evidence, he said, that "the structure and functional organization of parts of the central nervous system may be modified by changes in the internal and external environment. The chemical capacity to connect between neurons," he said, "appears to be altered by experience, and represents, in a sense, a type of learning."

In order to learn, however, the computer-like brain requires a programmer, as Dr. Victor Dennenberg explained. In most cases this programmer is the mother. There are now indications that the mother/infant (or care-giver/infant) interaction, in the earliest days, shapes not only the initial behavior pattern, but also the electro-chemical circuits of the thinking process in the brain.

The question then arises: Is too much stimulation as damaging as too little? Research indicates that there can, indeed, be too much.

Sometimes incubators, for example, can bombard the premature infant with noise. "We are keeping alive 28-, 29-week old fetuses," said Dr. Dominick Purpura. "From 22 to 32 fetal weeks is a major period of dendritic differentiation in the cerebral cortex," he said. At this period of extraordinary extra development, he said, inappropriate stimulation or the absence of appropriate stimulation, may contribute to the retardation and other handicaps often seen in premature infants:

Dr. Felix de la Cruz reported that a group of Swedish investigators had measured the noise levels inside five different kinds of incubators used for intensive care of newborn babies. The study revealed 70 to 80 decibels of sound pressure.

Human adults, he pointed out, can tolerate only about 80 decibels of sound. Anything above that intensity results in sensory neural loss, regardless of duration.

The recommended standard acceptable noise level on a hospital ward in Sweden is, 30 decibels.

Discussions then moved on to mother/child interaction. This interaction is "like a dance between mother and baby," said Dr. Evelyn Thoman. She and others stressed the individuality of each child and parent, and dispelled the long-held belief that the child's mind is a "tabula rasa" or blank slate.

"Mother may control the interaction," she said, "or she may yield to a diaper-dictator, or they may each in a synchronous way, perceive the cues given by each other and respond appropriately."

(Infants are not "passive, reflexive recipients of environmental stimulation," according to Dr. Earl Butterfield, in a later presentation, "Rather, they actively process the sensory experiences and they act instrumentally to change them from the day they are born.")

Dr. Thoman described research on "organized" babies who send out clear signals that are easy to recognize and respond to, in contrast to "disorganized" babies whose behavior changes erratically and rapidly.

She illustrated these behavioral states with several actual cases. The mother of one of the "disorganized" babies eventually reacted by withdrawing, because her efforts to communicate were increasingly futile. The baby died of sudden infant death. The mother, quite naturally, felt guilty because she thought she had rejected the child. The truth was, said Dr. Thoman, "the disruptive role was played by the baby." The child had rejected the mother.

Another baby in the study did not like to be held, and reacted by becoming drowsy or fussy. When left alone, she was alert.

"This is the kind of behavior," Dr. Thoman said, "that mothers of autistic children describe."

She then introduced into the conference the importance of mother/child/professional interaction, especially in such cases.

"If someone can perceive, and help parents perceive that there are certain stimulus conditions

under which this baby can be alert, and that she is very easily stimulated, then she may be brought around to the point where she can accept social stimulation," she said.

Dr. Harriette Rheingold concurred with the findings on mother/child interaction but also warned against "deifying the mother/infant relationship to the exclusion of the effects of father, siblings and culture on the child's development."

A warning of another kind was sounded by Dr. Leonard E. Ross and others: Despite the fact that intensive and comprehensive intervention can produce dramatic changes in children's behavior, the measures used to assess the changes are often sensitive to many other factors that influence the child's performance in other situations and over extended periods of time.

He saw improved school performance following intervention as possibly reflecting "student conformity or teacher expectations rather than changes in basic intellectual capacity."

Hence, he stressed research on the process of learning. He asked: "Are there differences in the way in which information is initially processed, transformed, rehearsed, stored and retrieved by the retarded child or the child at risk for mental retardation?"

He cited new insights into the cognitive control of eye movements and the perceptual unit processes in reading that have profound implications for the understanding of intellectual deficit. Another promising area for intervention that he pointed to is research on the processes and strategies used in the acquisition of language.

Dr. L. A. Leavitt described the collaborative research on learning processes that he and Dr. Ross are conducting.

In a related discussion, Dr. Earl Butterfield spoke of the necessity of cognitive and perceptual structures to be present before language can be acquired. "It is these structures which give meaning to the spoken form of a child's language, which he presumably learns through his experience with the auditory environment," said Dr. Butterfield.

He reported that studies indicate that babies can distinguish speech from nonspeech—from birth. And the more nonspeech auditory stimuli resemble speech, the more the infant responds. The implication, he concluded, is that infants should benefit from being talked to very early in life. (But not bombarded with speech, another participant cautioned.)

The theme of individual differences was again emphasized by Dr. James Gallagher. In embarking on a longitudinal study on intervention for high-risk children, the researchers became aware of the fact

that most longitudinal studies included two or more measures taken on the same sample of individuals one year apart. The purpose of the study was to try to understand child development.

"But development is not necessarily linear or predictable, we realize, when we study *individual* children over time and cross-sectional collections of large numbers of children," he said.

He confessed that behavioral scientists have tried to be like the physical scientists, with their laboratory control situations, "at the expense of observing what is going on in the child's interaction with his environment."

If the interaction between each individual and his environment were unchanging and predictable over time, he said, intervention could be done at any point of the developmental sequence, presumably with predictable results.

"But is this really so?" Dr. Gallagher questioned. "What about nurturance and independence? Does that relationship hold the same at age 2? 5? 15? How about peer values and the relationship of social behavior to the presence of the opposite sex? Does the interaction between these variables differ according to the age of the children and the developmental sequence? And don't all of these variables vary according to earlier events that have occurred? And is this series of interactions complementing the innate constitutional characteristics of the individual?"

Despite the fact that these realistic questions cannot be answered by unsolicited, short-term, massive cross-sectional studies, he said, we still believe the half-truth that their aggregate findings make up the wisdom of the scientific community.

In summary, he recommended careful and long-term financial support of longitudinal studies of three to five years that would cut across key developmental areas (language development, for example). He suggested that research organizations do the studies—"not just because individual investigators tend to die or move away, but because the range of talent that is needed to comprehend the full development of the child defeats any single investigator."

Dr. Todd Risley followed by speaking on the importance of a *working* language for the child—which is not always the same as classroom vocabulary—and the related importance of child-initiated learning episodes.

In classroom studies, Dr. Risley found that in working with disadvantaged, high-risk children, there was a rapid rise in the use of labels in their working language when conversation centered on things and normal activities that the children were required to describe. A child, for example, wants to play with a truck. Does he want the red truck? The blue truck? Big truck? Little truck? He has to describe the properties of the one he wants.

Then comes the reason for things. What are you going to do with it? Why do you need it? Thoughts grow into complex sentences.

A child's working language, said Dr. Risley, "is an indication of the way he approaches his environment, and it's probably a determinant of how the environment responds to him." If he doesn't use language concepts, he said, no matter how many language concepts he *knows*, other people do not tend to respond to him.

One of the keys to teaching children who are retarded in language skills, he said, is to engineer an environment which captivates them and engages them in ongoing activities which thereby increase the frequency of incidental teaching episodes.



Dr. Donald Baer reported on a research project with children with more serious problems than a lack of language skills—hyperactive children with short attention spans, aged four to about eight.

The first requirement, he said, is a potent reinforcement system used all day, day after day, but one not requiring special techniques or materials. Although motivational, the program can gradually be discontinued.

He described how these hyperactive children are taught to work at length and to completion of each task assigned.

In addition to teaching the elemental skills and content needed for school entry, Dr. Baer's program also works on behavioral quirks, such as a strange gait that one child had, that was changed to normal by a daily half hour of roller skating for an extended time.

The home program reinforces the classroom procedures. Parents are taught how to react constructively to the child's desirable and undesirable behavior, and how to diminish token reinforcement until correct social behavior itself is the sustaining reinforcer, said Dr. Baer.

In his discussion, Dr. Earl Schaefer suggested that professionals can be far more cost-effective if they try to change the parents' behavior toward the child, than if they try to change the child's behavior through direct intervention. There needs to be a working triad of mother/child/professional, he said.

The mother's attitude toward the child can be a strong force in positive or negative reinforcement, Dr. Schaefer said, adding, however, a note on the unpredictability of human nature. He recalled a situation in a longitudinal research project that illustrated diametrically opposite maternal attitudes. One mother rejected and ignored the child; the other was very accepting and loving. "Then we broke the research code," he said, "and found it was the same mother."

"I think it's the early environment, *plus* the continuing environment that influences the child," he said, in pointing out the need for more intervention research that examines the effect of a variety of environmental influences.

He also called for a close look at what professionals and institutions are doing that may be harmful or, at best, ineffective.

In our hospitals today, said Dr. Schaefer, illustrating his point, we are separating the mother from the infant in the first days and weeks of life—a practice that may do more damage to the infant than we can counterbalance by later corrective intervention.

Dr. Lyle Lloyd also questioned professional practices. "Why don't we find out how the child's audi-

tory system is working before we start training procedures that frequently involve auditory signals?" he asked.

About one out of 15 or 20 premature infants have a hearing loss, he said, which seriously affects the incidental learning that comes naturally to others without handicaps.

He repeated the concern of other speakers for the effects of incubator noises, especially on hearing and communication ability.



DEMONSTRATION PROJECTS OVERVIEW

In giving an overview of demonstration projects presented at the conference, Dr. Ernest Gotts asked the participants to consider the consequences of a physical disability, confinement to a crib and/or sensory loss. "A child who is tremendously impaired is restricted in his ability to create a world that has overlap with anyone else's," he explained. "As a result, he doesn't develop a very effective communication system. He doesn't share much world with anyone else to communicate about. Communication means sharing. Development of an abstract language system enables us to be flexible in what we share."

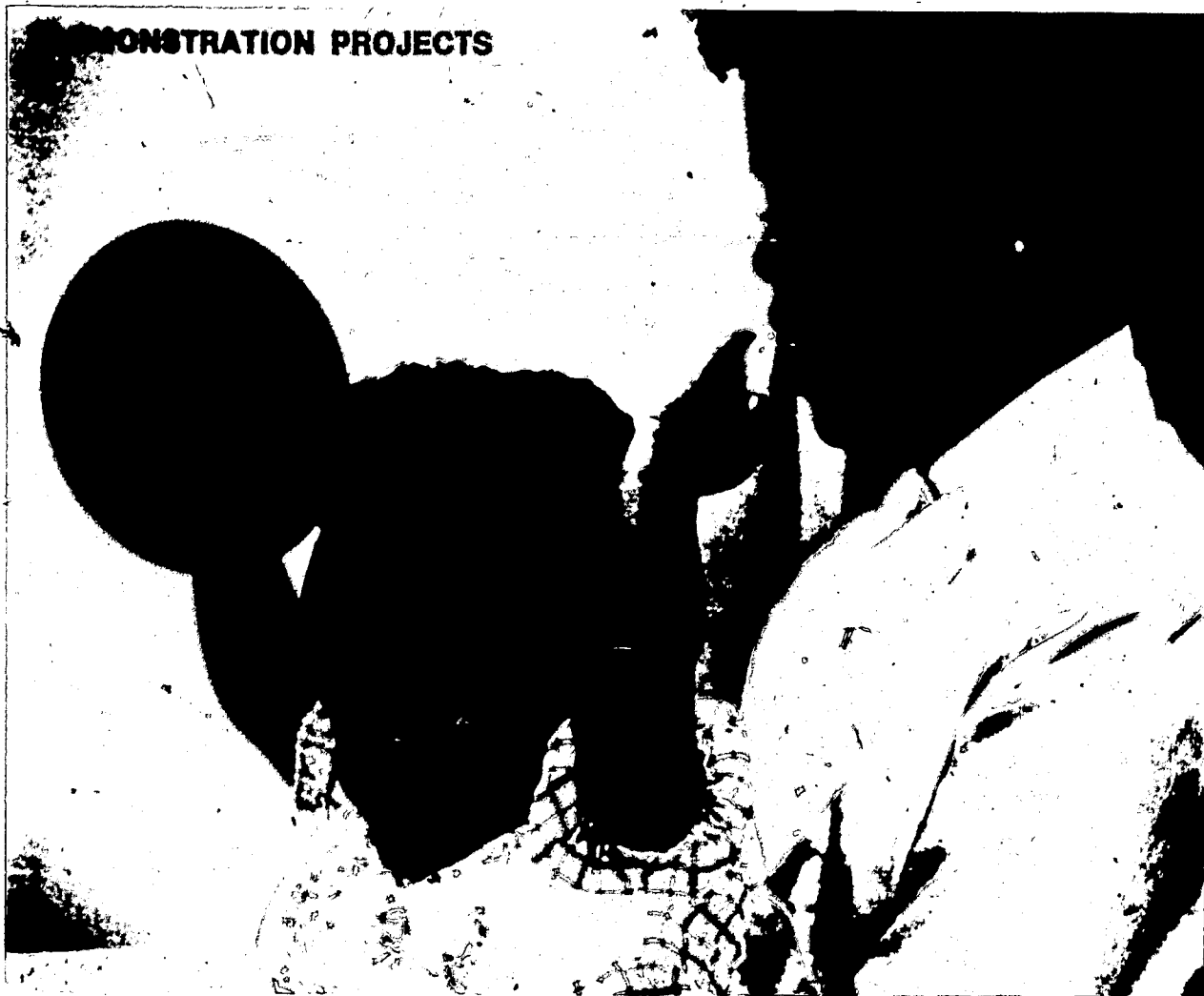
Dr. Gotts described the restrictions of that child's world, with nothing to stimulate motivation and curiosity or socialization and self-concept.

The young children who are confined because of handicaps do not explore, he said, do not initiate activities, do not imitate, or respond to adults or other children. They don't converse, can't sit still for even five minutes.

"I regard this behavior as the personal and social consequences of specific limitations of environmental stimulation—particularly the limitation in human contacts," he said.

He explained that the demonstration projects presented at the conference deal with behavior problems, lack of attachment, failure to develop sound human relationships. And the implications, he said, are twofold: "One, a direct intervention with the child; and two, a direct intervention with the child's immediate environment—his home and family."

DEMONSTRATION PROJECTS



EDUCATIONAL INTERVENTION WITH HIGH-RISK INFANTS

PRESENTORS: ARTHUR H. PARMELEE, M.D.
ETHEL R. KASS, M.A.

*Department of Pediatrics, School of Medicine
and Mental Retardation Center
Neuropsychiatric Institute
University of California, Los Angeles 90024*

This program is part of the Infant Studies Project at UCLA. The dual aims are to develop methods of identification of high-risk infants and techniques of intervention with such infants.

The Infant Studies Project uses a cumulative risk system to score the infant's performance from birth through nine months of age.

Selected infants determined to be high risk receive both clinical support services and a concentrated program of educational intervention for the following 14 months.

Rather than working either directly with only the infant or with the mother's emotional adjustment to the child, this program concentrates on improving the infant and mother interaction by training the mother to respond to the child's specific cognitive and developmental strengths and weaknesses.

The hope is that a mutually satisfying interaction of mother and child will produce both short-term and long-term results.

THE PORTAGE PROJECT: A MODEL FOR EARLY CHILDHOOD EDUCATION

PRESENTERS: DAVID E. SHEARER, M.S.
MARSHA SHEARER, M.A.

*Cooperative Educational Service Agency #12
412 East Slifer Street
Portage, Wisconsin 53901*

The project serves any child, from birth to age 6 (or until ready for school) with any type or degree of handicapping condition, who lives within the 23 school districts of rural south-central Wisconsin.

All instruction takes place in each child's home, with the parents as teachers. The parents are trained by a Portage Project home teacher, who may be either a professional or trained paraprofessional, using a precision teaching model.

At least three prescribed behaviors are targeted for learning each week. At the end of the week, the home teacher records data on achievement of the goals.

Parents are taught what to teach, how to teach, what to reinforce, and how to observe and record behavior.



PROGRAMS FOR DOWN'S SYNDROME CHILDREN

PRESENTORS: ALICE G. HAYDEN, PH.D
VALENTINE DMITRIED, M.A.

*Experimental Education Unit
Child Development and Mental Retardation Center
University of Washington
Seattle, Washington 98105*

The purpose of the program is: To develop and use sequential programs for increasing the children's rate of developing motor, communication, social, cognitive and self-help skills. The primary program emphasis is on bringing the children's developmental patterns as close as possible to "normal" children's performance.

The individualized curriculum is based on each child's observed and measured performance. He is not expected to acquire a new skill until he has mastered its prerequisite skills. Behavioral objectives are established for the child by teachers, parents, and consultants.



THE INFANT, TODDLER AND PRESCHOOL RESEARCH AND INTERVENTION PROJECT

PRESENTORS: WILLIAM A. BRICKER, Ph.D.
DIANE D. BRICKER, Ph.D.

*George Peabody College for Teachers,
The John F. Kennedy Center for Research
on Mental Retardation and Human Development
Nashville, Tennessee 37203*

The program, based on Piaget's concepts of human development, is designed for children from infancy to school age who are moderately to severely retarded or disturbed. An equal number of children who are developing normally take part in the program. Participants are from a wide range of socio-economic backgrounds.

The center provides individual education for each child, geared to his own developmental level, in language, motor, sensorimotor, and social skills. Parents are trained in behavior management of children prior to their training in the core classroom curriculum so that the center's program can be continued in the home.

Parents with special needs are given assistance in budgeting, using community agencies and obtaining needed medical and dental services.



MEETING STREET SCHOOL PROJECT

PRESENTORS: ERIC DENHOFF, M.D.
IRMA HYMAN, M.S.S.

333 Grotto Avenue
Providence, R. I. 02906

The Meeting Street School Parent Program for Developmental Management is a comprehensive, therapeutic-educational program designed to meet the developmental needs of children from birth to three years of age. Disabilities vary from the severely disabled, multiply handicapped baby to the relatively normal child with mild behavioral problems. The program has provided service to over 1,000 infants since its inception 15 years ago.

Its goals are:

- (1) To provide a community resource to evaluate atypical and "at-risk" infants.
- (2) To provide a comprehensive developmental management program for infants and their parents through various service models.
- (3) To offer service to the infant's parents that will enable them to understand their child's disability, and to participate in a program designed to help achieve the child's highest potential.
- (4) To involve the agency in an advocacy role with various other voluntary and official health, education, and social agencies in order to plan and provide for a continuity of appropriate services, and to foster the concept of the "rights of infants."



EARLY INTERVENTION FOR HEARING IMPAIRED INFANTS AND YOUNG CHILDREN

PRESENTER: KATHRYN B. HORTON

*Bill Wilkerson Hearing and Speech Center
Vanderbilt University School of Medicine
Nashville, Tennessee 37212*

The program emphasizes the detection of hearing impairment in infancy, followed by immediate intervention in the form of an intensive parent teaching program which stresses the maximization of residual hearing in order to enhance natural language acquisition.

There are two major components: (1) the Mama Lere Parent Teaching Home for infants and children under age 3 years, and (2) the acoustic preschool for children from 3-6.

The first program concentrates on parent instruction involving demonstration teaching in the child's natural environment, intensive audiologic monitoring of the child's hearing, and use of hearing aids.

In order to provide peer stimulation of language and communication skills, classes for the younger children include an equal number of children with normal hearing. Classes for older children emphasize individual and small group instruction supplemented by placement for one half day in a regular kindergarten.



THE READ PROJECT

PRESENTOR: BRUCE L. BAKER, Ph.D.

*Read House
Harvard University
Cambridge, Massachusetts 02138*

The Read Project Series consists of an Assessment Booklet and ten self-instructional manuals for parents of retarded children. Subjects covered are those for which parents expressed the greatest need for guidance: managing behavior problems, toilet training and other self-help skills, developing speech and language skills, and teaching constructive play.

The manuals are addressed directly to parents, with instructions presented clearly and humorously. Cartoons illustrate the material.

One hundred and sixty families, each with a retarded child ranging in age from 3 to 14, and living within a 30-mile radius of Boston formed the initial participants in the Read Project. The manuals are designed to be used by any parent of a retarded child within this age span. Special training is not required for the utilization of the manuals.





NATIONAL COLLABORATIVE INFANT PROJECT

PRESENTOR: UNA HAYNES, R.N., M.P.H.

United Cerebral Palsy Inc.
66 East 34th Street
New York, N.Y. 10016

This nationally organized collaborative project is designed to provide comprehensive services to handicapped infants and their families. Directed and coordinated by United Cerebral Palsy Associations Inc., it involves a consortium of centers already serving handicapped infants under age two, and their families. The project attempts to identify and use unique aspects of exemplary services provided by the centers, and incorporate them into service models.

Among the goals are the pooling of knowledge, skills and experience; the strengthening of the role of the family as the primary teacher and care-giver for children under age two; promoting team effectiveness in the design and implementation of services, especially where there are both medical and educational needs; informing both the scientific and lay communities about early intervention programs for atypical infants and their families.



CASE FINDING, SCREENING, DIAGNOSIS AND TRACKING



As the conference moved on to further discussions, Dr. John Meier addressed the group on case finding, diagnosis and tracking. "Intelligence is a relative thing," he said. "As our society becomes increasingly complex, there are more and more people who cannot cope effectively. Medical science has enabled more infants at risk to survive. Also there are large numbers of very young mothers who are not able to deal with child rearing intelligently. They are contributing to the fact that a number of children do not flourish, either through abuse or neglect or both."

Prevention of disability is more necessary than it has ever been before, he said. He added that the state of the art and science now makes it possible to identify at an early age at least some of the precursors of handicaps.

Dr. Meier reported that a cost-benefit analysis had revealed that not only laboratory screening for diseases but also screening for behavioral and other incipient disabilities can now be done for $\frac{1}{2}$ of 1% of the average cost of raising a child.

He suggested using existing systems as the initial nucleus for a massive screening effort, and cited as a possible model the U.S. Department of Agriculture's County Extension Service. Their child development specialists make regular visits to large numbers of people in sparsely settled areas. The agents can be trained in the use of screening instruments, he said. He also mentioned the network of University Affiliated Facilities and training centers which provide "the kind of clustering for identifying and screening and intervention" that has great promise.

"If you can get a responsive environment for an infant, including a mother and other physical accoutrements in the environment, it's incredible how this little computer is able to program itself," said Dr. Meier.

In comparing the brain to a computer, he asked: "Where else can you find a computer that has over ten billion flip-flop circuits, occupies less than a cubic foot of space, will operate on the energy of a peanut for up to four hours, is completely mobile, and is produced with unskilled labor?"

Dr. Arthur Parmelee's subject was diagnosis of high risk, and he outlined what a useful risk scoring system might encompass.

The system would (1) score pregnancy and neonatal biological advance and behavioral performance in additive fashion; (2) assess the infant in the first

months of life to sort out those with transient brain insult from those with brain injury or those who remain deviant; and (3) reassess the infant, primarily on a behavior basis, later in the first year of life.

The fact that there is no single predictor test supports the merit of a cumulative risk score, he said.

Following Dr. Parmelee's presentation, May Aaronson discussed the "enormous potential" for impact on early intervention of the Early and Periodic Screening, Diagnosis and Treatment Program (EPSDT), which is part of the Federal-State Medicaid Program.

She said that the EPSDT program necessitates major communication and collaboration among health and welfare professionals and parents, and provides "an extraordinary opportunity for upgrading the quality of parenting through parent-oriented education."

Dr. Theodore Scurletis described North Carolina's Comprehensive Developmental Health Services. He stressed the need for individualized, longitudinal and accessible services, in order to transfer scientific information into practical realization.

The North Carolina array of community services, he said, emphasizes case finding and educating the community; early and periodic screening; ongoing personal contact to teach the families what services can do for their children; and monitoring and assisting them in obtaining those services that are necessary.

Our health care in this country is failing, he said, "not because of lack of services, but because of lack of educating the population who are at greatest risk in the use of these services."

Dr. Scurletis listed five characteristics of mothers at risk: (1) under 18, over 34; (2) three or more children; (3) education less than ninth grade; (4) pregnant out of wedlock; (5) delivered a previous child born dead or a child born alive who is now dead. "We are trying to educate the population to the fact that if you have even one of these characteristics, you are definitely at risk, so seek service," he said.

Dr. T. Berry Brazelton presented overview comments of the previous discussions, and added some further insights.

"We should look for coping strengths," he stated, "and put the labels on them, not on the pathology." He suggested that professionals approach a mother/child interaction with an entirely new nonmedical model that emphasizes the positives.

Expressing great empathy with the mother, Dr. Brazelton said that mothers of handicapped children often feel responsible for the problem. "They feel guilty, helpless, hopeless." They feel that anybody

who would take the baby over would do a better job than they could, he said.

Professionals should interact with these mothers, he said, let them know that "we care, we see what they're going through, and we understand."

Give her an image of herself as an effective parent, he advised, and then get into the intervention program. Our goal, he said, should be not just the target child and his I.Q., but also the quality of a family's life.

U.N.C. CHAPEL HILL DEMONSTRATION PROJECTS

The conference participants then fanned out into Chapel Hill to make site visits to the University of North Carolina's intervention programs.

The first stop was a program of early intervention for biologically handicapped infants and young children, which combined research with training and service. The program also demonstrated the ways in which a University Affiliated Facility and a Mental Retardation Research Center can interact successfully. Dr. Donald Routh was the presenter.

Drs. David L. Lillie and Ronald Wiegerink presented information on the Frank Porter Graham's Developmental Disabilities Technical Assistance System (DD/TAS). The central staff of 20 works directly with the Developmental Disabilities Councils in all the States and Territories of the U.S. to help identify problems and develop solutions relevant to the Councils' planning and coordination of programs for developmentally disabled persons. When the central staff is unable to assist directly, they draw upon the DD/TAS's 500 consultants in a human services network.

Next on the itinerary was the Frank Porter Graham Child Development Center, for the Carolina Abecedarian Project, with Drs. Craig T. Ramey and A. M. Collier making the presentations. This project demonstrated a longitudinal and multidisciplinary approach to the prevention of developmental retardation.

Researchers, from a number of disciplines, are attempting to demonstrate that developmental retardation can be prevented. They also will attempt to explain how psychological and biological processes were affected by these preventive efforts.

The participating high-risk families receive: (1) Family support social work services, guidance with legal help, counseling in family planning, plus assistance in obtaining necessities; (2) nutritional supplements for each child in the center program; (3) medical care; (4) transportation to and from the

center; (5) payment for participation in psychological evaluations.

A matched group of families receive the same benefits, but their children do not participate in the day center's program.

Over 2,000 pieces of information are collected on each child in the project each year, ranging from the identification of microbes in the child's respiratory tract to the number of social agencies with which the families have contact.

The Center is establishing a comprehensive, open-ended, magnetic tape computer system which will allow access to any portion of the data from a remote terminal.

The hope is that such a breadth of information will help in the understanding of the high-risk child's development, and will aid him in developing normally.

LUNCHEON ADDRESS

"We have been attacking the problem of children at risk at too late a stage," HEW's Assistant Secretary for Human Development Stanley B. Thomas, Jr. told the luncheon guests during the conference.

He deplored the lag between the first suspected symptoms of retardation and intervention, and the fact that diagnosis frequently does not lead to treatment.

He cited a survey done by the National Easter Seal Society showing that after diagnosis, only 81% of the agencies assumed responsibility for placement of the child in needed programs. Only 42% of the agencies, he said, followed up to determine whether placements had been successful.

State clear objectives for clients, he advised, not only for the good of the client, but also as a means of measuring results. He also strongly endorsed parent participation in treatment programs, and a more effective use of paraprofessionals.

The greatest emphasis, however, was on environmental influences. "We need to spread the word," he said, "that it is possible to influence the child's intellectual growth by changing his environmental experience. At the same time, we must pursue research that will refine the techniques of such intervention."



"If you want to make [early intervention programs] widely available," he advised, "you must convince your State legislatures, your State Health departments, your State education departments, your county councils, your city councils . . . that your program is so cost-effective that the citizens and their representatives cannot afford to do without it."

STATE OF THE ART OF EARLY INTERVENTION

In introducing the State of the Art papers, Esther Morgan asked the questions she said she hoped would be answered by the papers to follow: Who has the responsibility for high-risk infants? Is it educators? Nurses? Psychologists? Doctors?

Dr. Paul Ackerman spoke on educational manpower. He estimated that 50,000 teachers of preschool handicapped children are needed.

The first problem, however, is to find these children, he stated.

Among other needs he referred to: Curricula demonstration models; research projects on preschool handicapped children and targeted dissemination and analysis of the research findings; a better defined State role; quality control; more inservice training of teachers, rather than just preservice training; more paraeducators.

In his report on pediatrics, Dr. Felix de la Cruz stated that the official goal of the American Academy of Pediatrics is the attainment by all children of the Americas of their full potential for physical, emotional, and social health.

"Are pediatricians properly trained to meet this challenge?" he asked.

He cited a 1964 study that attempted to ascertain the adequacy of pediatric residency training requirements. In this study, 60% of the pediatricians surveyed reported that management of disorders of mental and emotional development were frequently encountered in their practice; 35% of those surveyed felt they possessed a low level of competence to manage these problems.

In continuing care of chronic cerebral dysfunctions, such as mental retardation and cerebral palsy, 57% of the medical practitioners reported insufficient training opportunities were available. Almost three of every four practitioners reported insufficient training opportunity in child care activities in the community—the schools, courts, etc.

Dr. de la Cruz compared the results of studies done in 1934, 1959, and 1971, showing the relative frequency of diseases and conditions seen by pediatricians, as an index to the type of preparation needed.

In 1934, approximately 50% of the practice of one pediatrician was devoted to the care of infectious diseases; 35% involved routine care; .5% dealt with so-called psychological problems and/or those involving the central nervous system. (The pediatrician indicated that the .5% figure did not reflect the true prevalence of psychological problems.)

In 1959, a survey of 2,000 pediatricians showed that on a typical day, over 5% of the children seen had emotional or behavioral problems.

In a 1971 analysis of all 277,000,000 contacts between private practitioners and patients 0-15 years old, 30% of the contacts were for routine care of infants and children; approximately 27% for infectious diseases, and almost 10% for diseases of the central nervous system, sense organs and behavioral problems.

Of the patient contacts reported in the 1971 survey, 71% were in the doctor's office; 9% in the hospital, Dr. de la Cruz said.

Since the financial support of interns and residents comes primarily from hospital funds, he indicated, the nature of their training is determined largely by hospital needs—"not national or regional needs for pediatricians, nor educational needs of the graduate students themselves." Nor, he implied, is the type of training determined by patients' needs.

"With the extension of health care to encompass behavioral, developmental and cognitive problems," Dr. de la Cruz said, "it is evident that the medical model of care may not only limit but may even prevent professional intervention in these multifactoral problems."

Dr. Kathryn Barnard described a similar situation in the nursing field. The majority of nurses are trained in hospitals, she said, and consequently they lack a good base in preventive care or child growth and development. She encouraged consumers "to rebel" since the decision-makers respond more to them than they do to professionals in the field.

She cited several nursing programs that offer follow-up support to the infant through the first few years, or to parents of handicapped infants under stress.

The nursing department at the Eunice Kennedy Shriver Center of Fernald School in Massachusetts sees all referred newborns who are severely damaged, or infants whom the parents have decided to place outside the home, she said. The nurses help parents cope with the grief of having a child who is not normal, or a child they are giving up, or one who has died.

"We have a real obligation here," said Dr. Barnard.

Western Reserve, she reported, is now following

for six months all parents of infants who have died in the hospital. She said that Denver General Hospital has public health nurses follow 95% of the infants born there, and 100% of all the high-risk infants.

She echoed the concern that several participants had expressed for the premature infant in an incubator. She cited the possibly damaging effects of such an environment, and the difficulty of family and infant to attach to one another after such prolonged separation. She strongly recommended parental involvement with the infant while he is in an incubator.

Another suggestion Dr. Barnard offered was the installation in each newborn nursery of a nurse whose special job it is to provide developmental care and supportive work with parents. And she also advocates more masters level nurses who are trained in predictive infant and family care.

Following a discussion of the Developmental Disabilities Division by its director, Francis X. Lynch, there were presented some perspectives on the "state of the art" of early intervention.

"The best way I can describe the parent's perspective," said PCMR Member Louise Ravenel, "is to go back 15 years when I was a very scared, broken-hearted mother of a brand new retarded baby boy."

She recounted her feelings of grief, rejection and guilt. Although her family physician advised taking the baby home, "and love him just like the rest," several other physicians and other professionals later recommended putting him in an institution. The family took him home—"the best thing that ever happened to my other five children."

"New parents going through this crisis, vitally need the emotional support and professional intervention that I did not receive 15 years ago," she said. "When it is the informed opinion of professionals that your child has true value and worth, and has potential for growth, then the child begins to have value and worth in the eyes of the parents. And parents can become partners with the professionals in helping this child to grow to the highest level possible for him."

As he presented the educator's perspective, Dr. Godfrey Stevens noted that when compulsory education legislation was introduced, about 100 years ago, the Governor of Wisconsin was one of the Governors who vetoed the bill, announcing that compulsory education was un-American.

"Whoever made the elegant statement that it is the responsibility of the State to educate all of the children of all the people started a massive system of education, probably for the first time in history," he said.

The starting age of six was chosen, he explained, because in rural America at that period a child of that age could be expected to get from home to school and back without too much difficulty.

Age became a rather critical notion, he continued, because ultimately, when we use tests which deal with chronological age and mental age, those numbers become magical predictors of success or failure.

"Whole systems of instruction were built on the notion that you can't teach a child anything until he has a mental age of six," he said, adding that in Scotland, the system of instruction is based on a starting age of five.

He noted one often repeated concept of the conference: the very young child is probably as viable and ready for education as he ever will be the rest of his life.

It is critical for educators to realize this fact, Dr. Stevens said. He warned that there will probably have to be a major shake-up in the structure of American education, requiring new kinds of legislation to accommodate to this truth.

In addition, he predicted that the days of rejecting defective children from the educational system are over.

He deplored the rigidity of such "instructional configurations" as the perpetuation of the German grade school system, in which children who are six years old are in first grade, seven years old in second grade, and so on in chronological sequence, regardless of ability. The same kinds of instructional configurations exist in the universities, he said, as he pointed out the difficulties of obtaining a comprehensive, cohesive view of early childhood development in a systematic way at the university level.

"If we're going to start educating children from birth on," he concluded, "we'll probably have to change the habits and value systems of people in order to realize these new educational concepts."

Dr. Pamela Coughlin based her presentation on handicapped children in Headstart programs.

Headstart has gone beyond its mandate to fill 10% of the slots with handicapped children, she reported.

The largest group of handicapped children enrolled in full year Headstart programs—35%—are speech impaired, while health impaired or developmentally impaired children account for over 20%, according to Dr. Coughlin.

She told the group that about one-third of the handicapped children in Headstart were diagnosed before entry, while two-thirds were diagnosed as handicapped in some way, after entering the program.

In general, she said, Headstart program staff and parents believe the integration of handicapped and

non-handicapped children is beneficial to both groups of children.

Dr. G. Allan Roher, remarking, tongue in cheek, on earlier comments made at the conference, said it was interesting to note some 50 years after the industrial revolution and Sigmund Freud, and around \$700,000,000 spent on social, behavioral and educational research, that we've discovered that children do, indeed, have parents. And, he said, we have to listen to them if we want to realize optimal results.

"We have at times taken ourselves a bit too seriously in some of our efforts that we call research," he said, "and sometimes have overlooked what the elders would call good common sense."

One of the major obstacles that became apparent in the conference, as he saw it, was the inability of professional people to agree on a common approach—a necessity if the agents for change are going to implement progress on a large scale.

He envisioned two continuing streams of effort moving in parallel lines in the future:

(1) Continued emphasis on stimulation of basic research efforts (in contrast to what is often good clinical service under the guise of research).

(2) The mass application of agreed-upon knowledge. To move from isolated "Islands of Excellence" to broad programming, professionals must agree on the use of only those approaches which work well, even though they may not be perfect.

"We will have to strip off the jargon and the many research variables," he said, "and build a kind of basic curriculum for manpower preparation and inservice models to realize mass application of techniques."

He reported that it would cost \$9,000,000 to institutionalize 20 mentally retarded persons an average of 60 years. However, using the techniques described in the conference and creating a comprehensive community services model, the cost of caring for these same 20 people would be \$3,200,000—a savings of almost \$6,000,000. More importantly, the 20 would have a far higher quality of life.

We need leaders who can translate these kinds of things into organizational systems, Dr. Roher concluded.

Eloisa Garcia de Lorenzo offered an overview of some early childhood programs in South America. She described the practice of sending premature babies home with the incubator in Caracas, Venezuela. A trained nurse makes frequent visits to the home to teach the mother how to interact effectively with the baby, as well as teaching basic care. Despite low



economic standards the infection and mortality rate of the babies taken home in the incubator is far lower than that for babies kept in the hospital.

She discussed other innovative programs, including mobile clinics with team specialists in Panama; day-care demonstration centers in Brazil; laws making breast feeding compulsory in Uruguay and Chile.

Mrs. de Lorenzo gave a graphic picture of conditions around Lima, Peru, in the new paper shack villages inhabited by people who have migrated from the jungles and mountains, and have found no place to live. There are massive problems in these "pueblos," she said, including extremely poor nutrition and no child-care programs. "Babies are often left in the care of children four or five years old for the whole day," she said.

With the participation of the people, the educators and doctors have started education programs and intensive day-care centers in these villages. The main point is to help these families handle what they have, as the first step in making basic changes in the environment. The youngsters who take care of the babies are being trained to get better nutritional value even from the minimal food that they have, and to talk to and otherwise stimulate the babies in their care.

She spoke of "how good it is for people to work together from different countries. Then we have a

different image of what an American is, because the image at the beginning is United Fruit and capital investment . . . machines and cold technology. We develop defenses," she said.

"And then [through such meetings as this] we see another type of American. Absolutely different. This is a people-to-people relationship through professional people . . . who talk to us to help us or to discuss with us the way we care for our minorities."

Those who have come to South America "to see the work there are never the same afterwards," she said. "And we were never the same after they were there." She pleaded for more international cooperation. "One of the best things I will take from here is the knowledge that you really care and understand."

CONFERENCE COMMITTEE REPORTS AND RECOMMENDATIONS

On Tuesday evening, participants had met in separate groups to discuss and make recommendations on education, pediatrics, nursing and habilitation, community development, parents, and research.

Prefacing his report on the education committee's recommendations, the chairman of that group, Dr. Willard H. Hartup, commented that early childhood classes and programs are concerned with the basic processes of perceptual development, cognitive development, and learning.

The developmental status of the individual child is the cardinal principle. "This contrasts sharply with the emphasis on graded subject matter transference which has been the basis of the development of most of the strategies in the rest of education," he said.

Consequently, he said, more and more educators of a variety of sorts—not only special educators—have looked to early childhood education for plans and ideas.

The education committee's recommendations:

- (1) Expand at a rapid rate the capabilities of our society for educational intervention in the lives of young children at risk;

- (2) Plan the intervention within the context of theoretical advances and professional efforts directed at all children;

- (3) Predicate these efforts on the thesis that effective intervention efforts are multidisciplinary, in spite of the difficulties in achieving that end;

- (4) Attempt to solve the manpower needs in intervention in at least two respects: Increased number of professionals, and improved models of professional preparation;

- (5) Continue and expand research in the processes of acquiring language, the pure attachment system, memory development and the perceptual basis of reading;

- (6) Hold further conferences of this sort.

The pediatrics committee was represented by its chairman, Dr. Paul Pearson, University of Nebraska at Omaha.

The pediatrics committee recommendations:

- (1) The goal of the pediatrician must be to do everything within his professional competence to insure the optimal physical, cognitive, emotional and social development of the child.

- a. He must play a vital role—but not in professional isolation—in all aspects of child care: Prevention (conditions which place the child at high risk and early identification of the high-risk infant and the infant with a disabil-



ity); assessment and definition of the problem; development of the management plan.

(2) Evaluate as soon as possible, the state of the art of child development programs within departments of pediatrics and medical centers.

a. Identify available models of training to determine factors that make a program successful or unsuccessful;

b. Include in the study team a pediatrician knowledgeable in developmental pediatrics from an academic background, a pediatrician familiar with primary care, and a social scientist;

c. Visit all departments of pediatrics, and, in addition, do a sample of practicing pediatricians to determine their perception of needs for training;

d. Hold a conference to deal with results of the study and make recommendations;

e. Get the information to the pediatric power structure.

Results of the nursing and rehabilitation meeting were reported by Barbara Bishop, who chaired the group.

The nursing and habilitation committee recommendations:

The Family:

(1) Focus programs for infants at risk on the family;

(2) Identify positive support systems to provide help for mothers;

(3) Involve parents and the family in the education, evaluation and decision-making process regarding themselves and their child.

Education:

(1) Initiate family life courses from kindergarten through grade 12, with emphasis on parenting;

(2) Include courses on the exceptional child in the public education of children and adults;

(3) Plan common learning experiences, both didactic and clinical, for all disciplines relating to infants at risk and their families;

(4) Introduce continuing education for all professions and disciplines relating to the child at risk.

Professionals:

(1) Encourage interdisciplinary work;

(2) Validate, through research, what interventions work, and who can deliver the services;

(3) Encourage dialogue among researchers and clinicians;

(4) Pro-rate the cost factor in any health care delivery system.

The community development committee presented its report through its chairman, Dr. Ronald Wiegertink, who stated that the group focused primarily on community services.

The general recommendations of the community development committee:

(1) Get the existing knowledge and expertise into delivery systems now, and design them to maintain high quality while serving much larger numbers of high-risk children and their families;

(2) Develop improved community services for the rural and urban poor who have received so little.

Specific recommendations:

(1) Develop a public information campaign to promote community and neighborhood service systems;

(2) Design public policy to make resources available to provide comprehensive community services, and promote laws and appropriations which lead to services such as mandatory early screening and assessment of all children;

(3) Establish networks of coordinated community services in all regions of the country, to include at a minimum: Crisis support, transportation, respite care, foster care, adoptive support services, family planning, and parent education;

(4) Insure that someone or a group take responsibility for every high-risk child and family to coordinate many of the existing but uncoordinated services.

H. Rutherford Turnbull, III spoke for the group he chaired, the parents of handicapped children. "We are families at risk," he said. Rather than presenting recommendations, he listed some of the needs of parents, as expressed by the group.

Among the needs of the parents group:

Training on the need for early intervention and means of getting into the early intervention system;

Training on the nature and causes of mental retardation;

Parent survival skills;

Expansion of the parent/child/professional triad to include the total family, with parents participating in training programs;

The parents' need to listen and the need to be listened to;

Parent-to-parent referral systems for support and information;

Longitudinal follow-along services—not just for the child from 0 to 5;

More research to help prevent and ameliorate mental retardation;

Increased professional sensitivity to parents' opinions of child's condition and behavior;

Less professional jargon—"We ask you not to speak in tongues;"

Keep parents involved.

Sidney W. Bijou, Ph.D., chaired the research committee and presented their recommendations as follows:

(1) Design a new federal mechanism that is concerned with research on delivery systems and utilization of findings;

(2) Ease the access to both normal and retarded children for research purposes where no danger or deception is involved;

(3) Make the universities more aware of the needs for research on risks to children, make them aware of current information so that they can provide adequately trained people;

(4) Devise improved methods of communications between researchers and parents, with parents' groups systematically and continuously reviewing federal research policy and programming;

(5) Clarify the fact that research for high-risk children applies to any child that is in a sense deviate in development; the labeling and specific diagnosis mean very little at that stage.

PCMR Member William B. Robertson commented on minority problems, saying that when we talk about children at risk, we are talking mostly about black, Chicano, Puerto Rican, Indian, and white Appalachian children. And when we speak of bringing people with physical and mental handicaps into the mainstream of American life, he said, we must resolve to bring all segments of the population into the mainstream.

Dr. Louis Z. Cooper, who had chaired the session, took the chairman's prerogative to make the final statement of that session. "It is my bias," he said, "that the concept of high risk is useful only as a step toward development of full service programs for children. In fact, those children whom we currently label 'high risk' or 'at risk' are the ones who most easily fall through the cracks, who are always going to be the last to be served. Until full service programs for all children are in place and operational, we never will adequately reach the 'high-risk child' with the quality of care to which they are entitled."

SUMMARY

In a review of the proceedings, Dr. George Tarjan, commented that an "ideal" preventive program would assure that every child be born with a healthy central nervous system, that he will have a set of early experiences that encourage intellectual, emotional and social growth, and that he will be protected from physical and psychological damage. Since no child can escape from all harm, he said, the program must also strive to strengthen the child's ability to cope with what befalls him.

"Unfortunately," said Dr. Tarjan, "we are far from even an approximation of this Utopian state."

Information brought out in the conference, however, promises significant progress, he said, citing, for example, indications of interdisciplinary collaboration, especially in major research strategies involving broad attacks on interrelated issues.

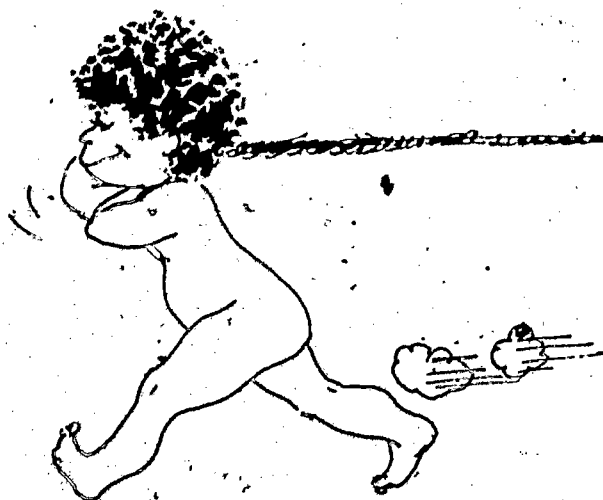
In the real world of clinical practice, he said, the physical and behavioral dimensions are fully interlinked. In general, one cannot observe the physical organization of the brain except through its behavioral expressions, and, he continued, one cannot adequately assess behavioral impairments without taking into proper account the presence and nature of possible organic disorder.

Interventions, even when conceptually restricted to one domain, unquestionably influence the other, he said, using as an example the fact that drugs modify behavior, and learning in some fashion alters the biochemistry and physiology of the brain.

"Behavioral interventions, particularly during very young ages when the central nervous system is still undergoing development, could positively influence the quality of the brain's somatic organization," he said.

Moving on to other areas, he sounded a warning on the inherent dangers of mislabeling to those doing any broad scale early screening and intervention program, and suggested that in the borderline areas where diagnosis can be difficult, he would prefer to miss a few children who are retarded rather than risk false labeling of children who are not retarded.

Dr. Tarjan stressed individual differences and the limited scientific understanding of these differences, especially among high-risk children. An understanding of the child's immediate environment is equally essential, he said. "Early intervention programs are composed of a series of external stimuli to which the infant is expected to respond," he said. "His responses in turn evoke modifications in his environment, resulting in new stimuli; and the cycle continues in this fashion."



He pointed out that in many respects, the process is very similar to the ordinary mother/infant interaction—and she, too, is as variable as the infant. The behavior of each is constantly modified by the responses of the other, said Dr. Tarjan.

After defining the difficulties of adequate evaluation of early intervention programs, he still held that continued evaluation is essential to lead us to more effective solutions. He called for more data on natural growth and development, since infants or young children change over a period of time with or without intervention, and simply as a consequence of growth.

"We do not have all the answers," he said. "But we do know enough to promise to the next generation of high-risk infants that there will be progress rather than regression," he said. "We can, and we must assure each child the best opportunities for maximal development and for a better quality of life."

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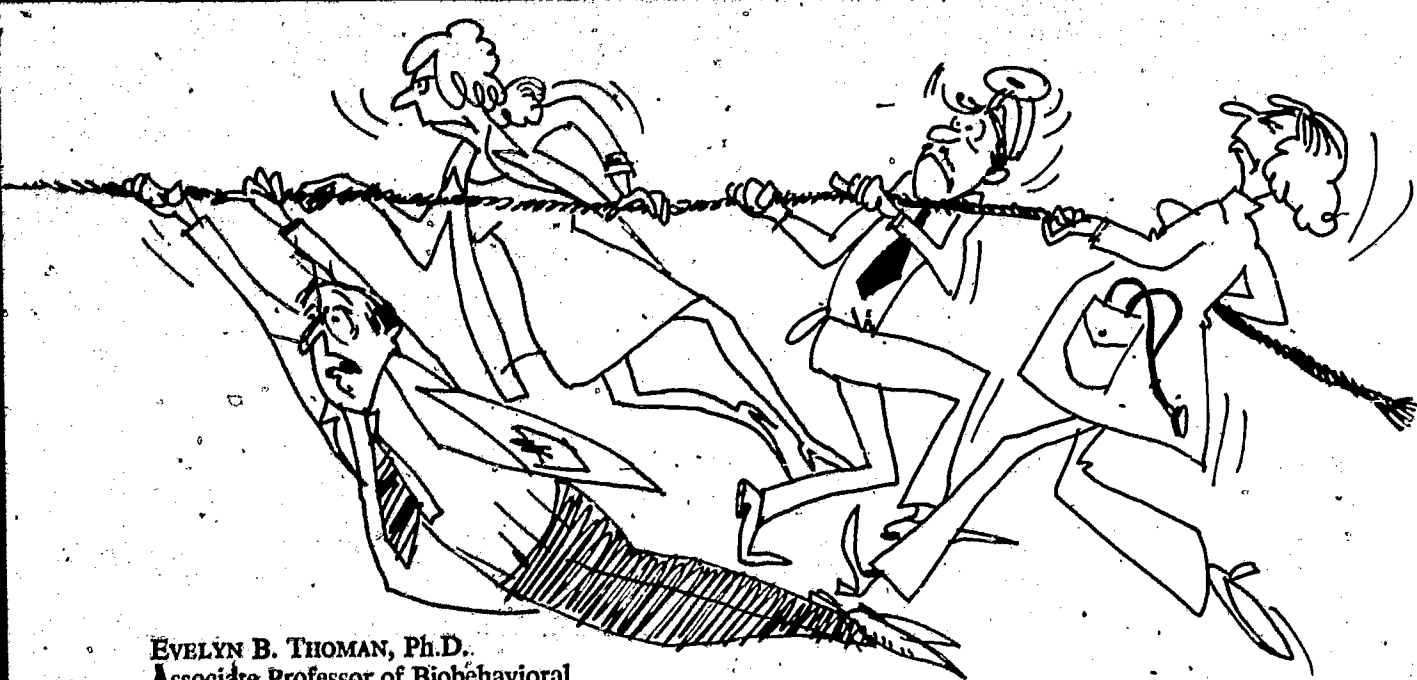
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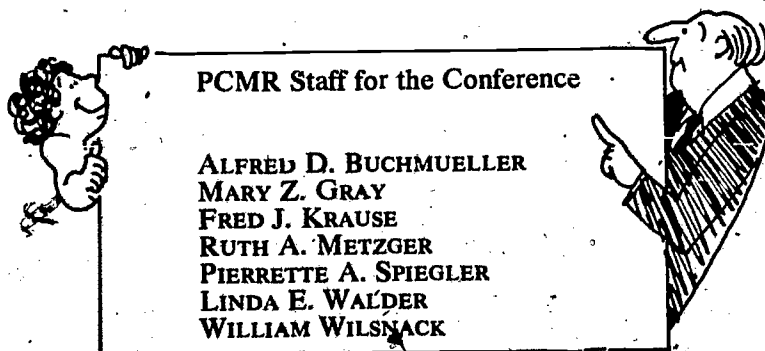
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